



# Massachusetts ME/CFS & FM

ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985

## ***Mass PI: Improving Pain Care through Education and Policy***

***Cindy Steinberg , Policy Council Chair***

***Jackie Nathan, Nurse Practitioner, Pain Management***

***Michele Matthews PharmD, Member-at-large***

## ***Sunday Conversations***

***with MassME***

**June 23, 2024**



# Housekeeping

- ❖ We respect your privacy
- ❖ Please stay muted
- ❖ Put questions/comments in the chat
- ❖ A recording of the main presentation and Q&A will be posted

*We cannot answer questions related to your personal or any specific, medical condition.*

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# Massachusetts ME/CFS & FM

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## ***Mass Pain Initiative:*** ***Improving Pain Care through Education and Policy***

Sunday, June 23th, 2024, 4 p.m. ET



**Cindy Steinberg**  
**Dir. Policy & Advocacy**



**Jackie Nathan,**  
**APRN-BC**



**Michele Matthews,**  
**PharmD, BCACP, FASHP**



# Massachusetts Pain Initiative

## *Improving Pain Care Through Education and Policy*

Cindy Steinberg  
Policy Council Chair &  
Director of Policy & Advocacy  
US Pain Foundation

June 23, 2024



# My Story

- More than 20 years ago, I was crushed in an accident at work where I was a corporate manager
- Opened a file drawer of a very large cabinet
- Unbeknownst to me, moving men stacked cubicle walls against the back of the cabinet
- Cabinet and walls fell on me & pinned me to the ground
- Accident tore & damaged nerves and ligaments in thoracic spine
- Left me with daily band of burning, gnawing pain across mid-back & muscle spasms when upright that never went away
- Pain & spasms can become severe after an hour upright



# My Search for Help

- Sought help for excruciating daily pain while holding on to my career
- Surgery not an option
- Tried nerve blocks, injections, PT, OT, Prolotherapy, braces, acupuncture, massage & more
- At best, told by h/c providers can't help you
- At worst, treated in a demeaning, dismissive manner, accused of being a malingerer simply by seeking help for debilitating pain
- Five year journey through h/c system until finally found a doctor who helped me



# Roller Coaster of Chronic Pain Treatment: Hope & Disappointment



- Torturous route “roller coaster” of trial & error investing time, money & energy to find a way to lessen the pain
- Research & try treatments, try to stay hopeful—only to have hopes dashed

# My Search for Connection

- Felt isolated but thought could not be the only one living w/ this much pain
- Hung sign at local library; starting a pain support group
- People started showing up; a few & then more & more
- With a myriad of conditions that result in pain: carpal tunnel, migraines, disc disease, rheumatoid arthritis, cancer, neuropathy, back pain
- Conditions I never heard of: CRPS, EDS, Marfan's, pudendal neuralgia, fibromyalgia, TMJ, vulvadynia, IBS, interstitial cystitis, etc
- Has been 24 years still going, more than 500 people have come to group
- Everyone had had to see at least 4-5 practitioners to find help, if they ever do



# Why Is Pain Care So Inadequate in the US?

## Root Causes

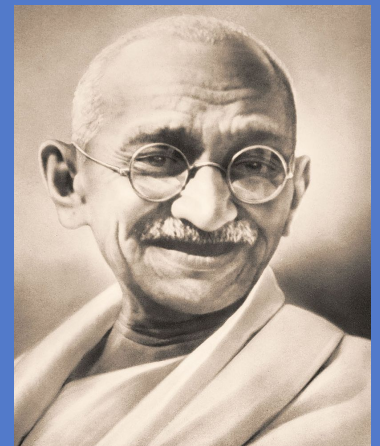
- *Underinvestment in Research* – Pain is the number one reason Americans visit their doctor, < 2% of NIH annual budget spent on pain research
- *Do Not Understand the Basic Mechanism of Pain in the Human Body*  
Pain is a neurobiological disease we do not fully understand
- *Lack of Specialized Physicians* – Less than 1% of doctors are specialized in pain management
- *Very Little Time Spent Educating Doctors & Other H/C Professionals About What We Do Know About Pain* – On average med students get 11 hours of pain mgmt education in 4 years of med school; veterinarians get 87 hours (*Pain & Therapy, Dec, 2018*)
- *Dearth of Highly Effective Treatment Options* – no cure & very few, if any treatments to dramatically reduce hi-impact chronic pain



# *“You must be the change you wish to see in the world.”*

## Mahatma Gandhi

- I have found inspiration from great advocacy leaders
- Strong belief that if you don't like something, work to change it
- After my own experience searching for help & that of my pain group members, decided to focus all my efforts on improving pain care in this country
- I have devoted my life's work to trying to do that, primarily through policy change at the state & federal level
- Largely because policy has the ability to affect many more lives than I can w/ my support group



# Fifteen Years of State & Federal Pain Policy Change

## MA State Examples:

- Drafted and Passed Law Requiring Continuing Pain Education for Doctors in MA - 2010
  - Doctors must take 3 hours of pain mgmt CEU's every 2 years
  - *Addresses: Lack of Pain Education for Physicians*
- Appointed By MA Governor Baker to Opioid Working Group - 2015
  - One of his first acts as Governor was to appoint this 17 member working group; I was the only one representing pain; chaired by HHS Secretary
  - Came up with 65 recommendations to address opioid crisis without restricting legitimate access or harming pain patients



# Fifteen Years of State & Federal Pain Policy Change

## MA State Examples:

- Added important pain provisions to the CARE Act - 2018
  - Required payer coverage of “a broad spectrum of pain mgmt. services”
  - DOI regs specified 2 additional medications and 3 non-pharma therapies
  - BC/BS added acupuncture & others added MBSR, chiropractic
- MCSTAP Program – state-funded consultation service for PCP’s to help manage pain patients



# Fifteen Years of State & Federal Pain Policy Change

## Current MA State Examples:

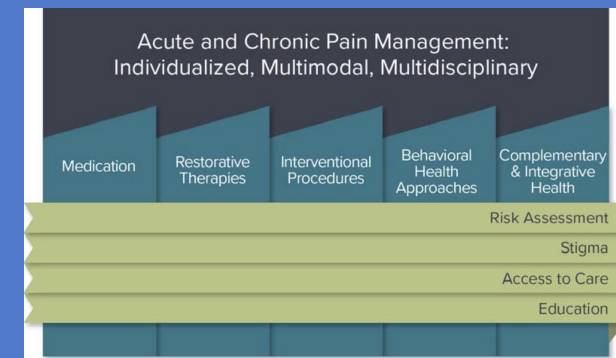
- Working on 2 bills in current legislative session
  - H.990/S.659 – proposed to remove prior authorization from pain mgmt treatments added to conform with CARE Act
  - H.4743 – requires provider education and patient information on “non-opioid treatment alternatives including restorative, behavioral, interventional, medications and complementary and integrative treatments.”
- Both of these bills were included in a large SUD bill passed by the MA House last week



# Fifteen Years of State & Federal Pain Policy Change

## Federal Examples:

- Appointed to serve on HHS Pain Mgmt Best Practices Task Force -2019
  - Congressionally mandated panel of experts to report on best practices for the nation
  - *Main finding* – best practice is individualized, multidisciplinary treatment plan w/ treatments drawn from restorative, behavioral, medication, interventional and complementary & integrative treatment areas
- Got a current federal bill introduced
  - S.2922/H.R.7164 – *Advancing Research for Chronic Pain Act of 2023*
  - Directs CDC to analyze, report on & annually update impt population health data and cost information on CP on a public website



# Opportunities to Participate

## Chronic Pain Support Group

- Free, virtual meetings, second Friday monthly, 11am – 12:30pm et

Learn more about our federal bill in a free webinar July 22, 1-2:30pm et and engage in our Virtual Advocacy Day, July 23<sup>rd</sup>

- We explain how and make it easy with pre-written e-mails and social media posts
- To register: <https://bit.ly/3XxYxFI>

Volunteer for MA State pain advocacy w/ MassPI Policy Council

Volunteer for federal or other state advocacy w/ U.S. Pain Foundation

[Cindy@uspainfoundation.org](mailto:Cindy@uspainfoundation.org)

Thank you for listening!





# PAIN NEUROSCIENCE

Jackie Orent-Nathan, ARNP-BC  
Pain Management Specialist



# How Pain Actually Works

## Why do we have a Nervous System?

- 3 MAIN COMPONENTS
  - Peripheral Nervous System (PNS)
    - Nociceptors (danger sensors)
    - GOVERNORS
  - Central Nervous System (CNS)
    - Spinal cord and Brain
    - GATE KEEPER
  - Brain
    - ~~PRESIDENT~~ ~~KING~~ ~~QUEEN~~ EMPEROR

# Nervous System and Pain



OUCH!!!!



# Nervous System and Pain

- **Governors**
  - **Purpose:**
    - Detect Threats
    - Keep us out of danger
  - **Types of Threats**
    - Mechanical forces
    - Thermal changes
    - Chemical changes
- **Governors send Information to Gate Keeper about the state of the tissues**
- **Gate Keeper may or may not relay that message to the Emperor**



# Pain or No-Pain and How Much

Age, Gender, Culture, and Genetics may play a role

Emperor has received messages from the Governors but needs more information

- Environment
  - Location, what else is happening around you, is there more present danger (for you or someone else)?, was your next bowl going to win the tournament?

# Pain or No-Pain and How Much

- Context

- Has this happened before to you or anyone you know (do you have a stored memory of this type of event)?, How important is your toe?
- Thoughts are messages too

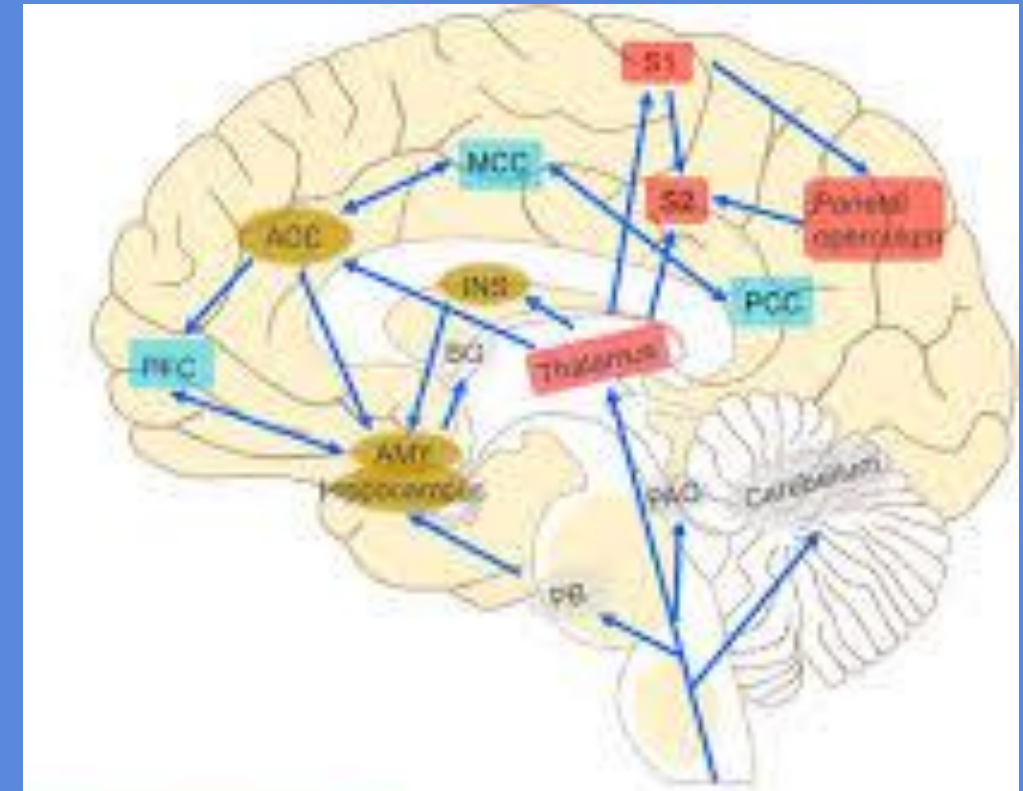


# Pain or No-Pain and How Much

The Emperor consults with hundreds of brain regions including thinking and memory parts

- The job of the Emperor is to conclude, based on credible evidence, whether or not to create pain

This all happens in milliseconds and is out of conscious control



## **Primary cortical pain matrix:**

The sensory discriminative aspect of pain (pain perception and location)

## **Secondary cortical pain matrix:**

The affective/motivational component of pain (empathy for pain)

## **Third cortical pain matrix:**

Cognitive/evaluative aspect of pain



# Systems Work Together to Manage Threat

Depending on level and kind of danger, the Emperor makes a decision  
What's the best way to Protect?

Pain:

- Motivate to escape, seek help, attract attention

Sympathetic Nervous System:

- Increased Heart Rate, mobilize energy stores, increase vigilance

Motor System:

- Run away, fight, protect damaged areas

Immune System:

- Promote healing, fight invaders, sensitize neurons

Endocrine System:

- Mobilize energy stores, reduce gut and reproductive activity



# Persistent Pain

## Nervous System Adapts (Neuroplasticity)

- Repeated messages from the Governors leads to changes
  - Nerve cells in the GATE KEEPER get better at sending danger messages to the Emperor
  - These nerve cells become more sensitive. Their receptors can stay open longer and they can increase it's manufacture of new Governors
    - Hyperalgesia
    - Allodynia
- The Emperor gets better at forming neural connections
  - “Neurons that fire together, wire together”
    - Neurotags or Neurosignitures are formed



# ME/CFS

- Governors in the Nervous System are alerted to threat, send messages to Gate Keeper
- Gate Keeper may relay those messages to the Emperor
  - Genetics, Gender, Age, Culture likely play a role
- Emperor weighs the evidence from incoming messages and from brain regions
  - Thoughts are messages too
  - decides what response is most helpful
- Nervous System Adapts with repeated danger messages, more Governors are created, Neurotags are formed and strengthened
- Other systems get involved
  - Activate Immune System: creates low-grade chronic inflammation
  - Activated Endocrine System: increased Cortisol



# Helpful Resources

## Videos on Neuroscience: [Lorimer Moseley](#) on YouTube

*“Body and Mind-the role of the brain in chronic pain”*

*“Pain, Brain, and Your Amazing Protectometer”*

## Books

*“Explain Pain”, David Butler & Lorimer Moseley*

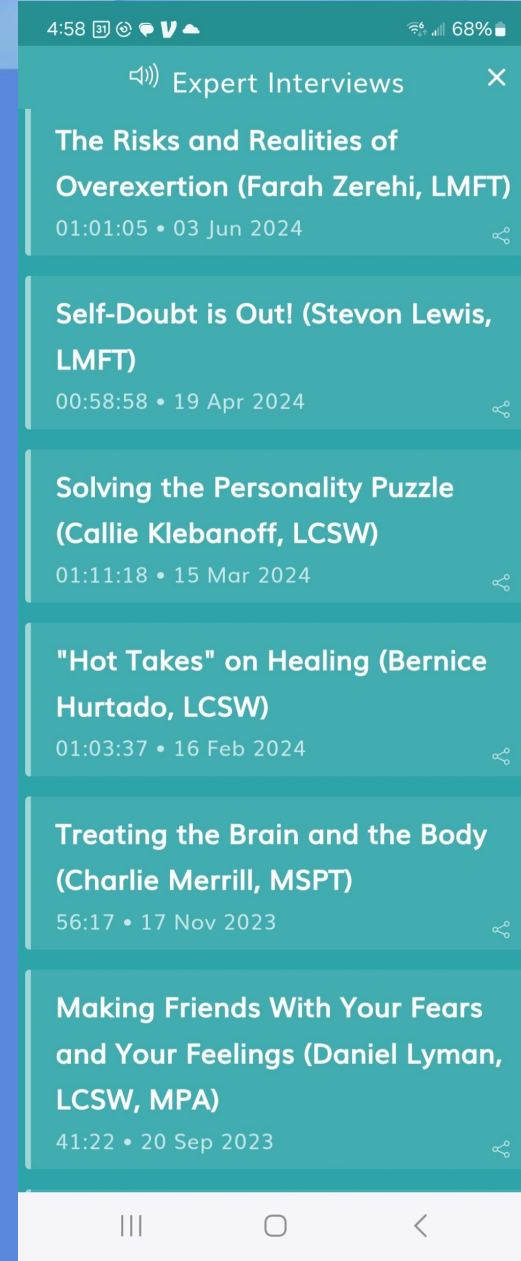
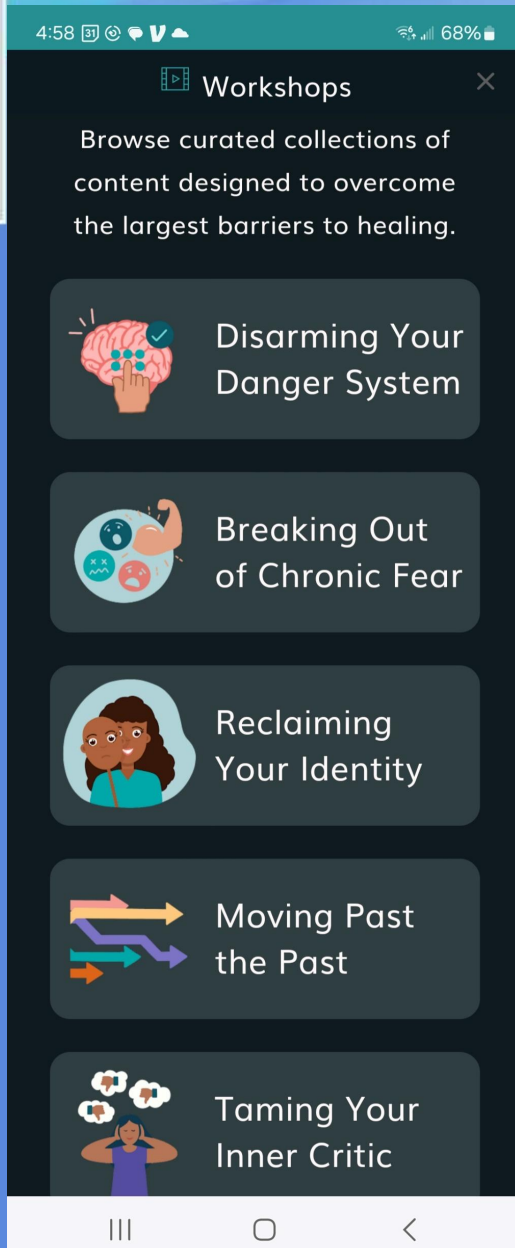
*“The Explain Pain Handbook: Protectometer”*

*“The Way Out”, Alan Gordon*

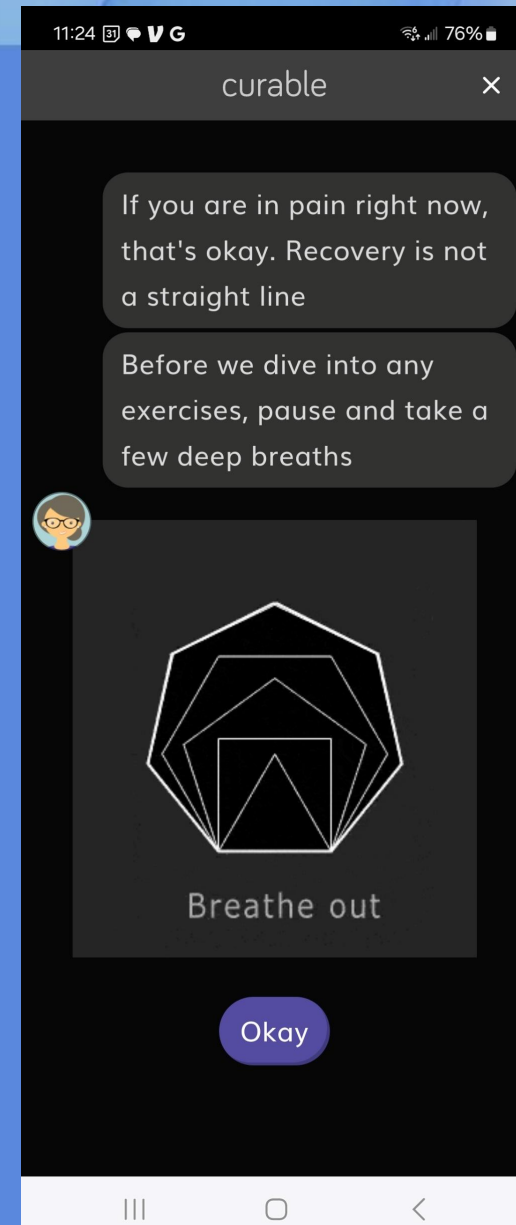
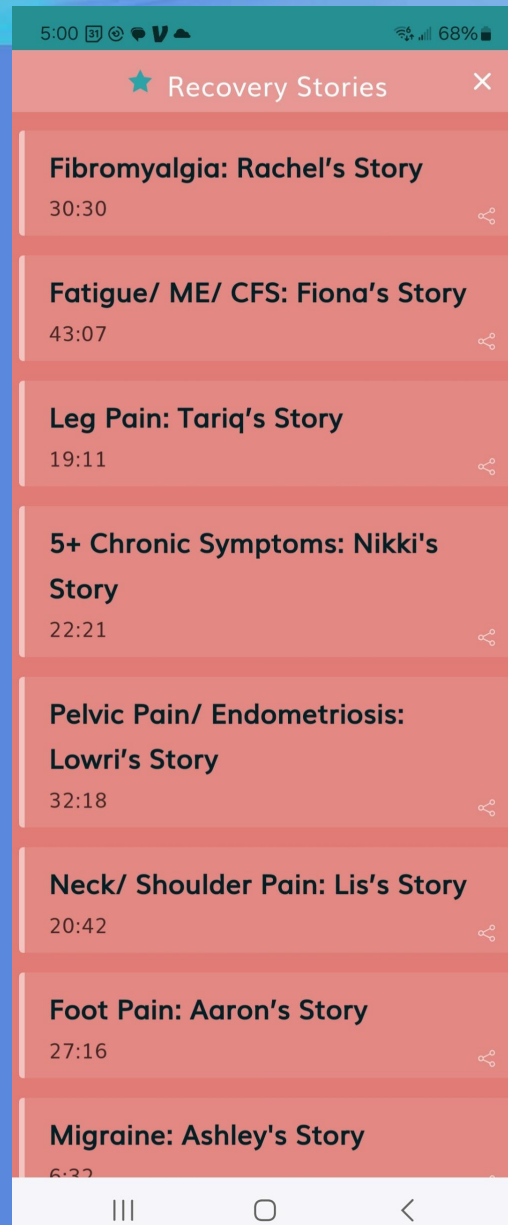
## Apps

*Curable (\$5.99/month)*

# Curable App



# Curable App





# Ins and Outs of Medications for Pain and Symptom Management


Michele Matthews, PharmD, BCACP, FASHP

Professor of Pharmacy Practice, Massachusetts College of Pharmacy and Health Sciences

Advanced Practice Pharmacist – Pain Management/SUDs, Brigham and Women's Hospital

Past President, Society of Pain and Palliative Care Pharmacists

## **Provider, Educator, & Advocate**



- 20 years of experience
- Professor of pharmacy practice
- Advanced practice pharmacist specializing in pain management and substance use disorders (SUDs) at Brigham and Women's Hospital

## **Researcher**



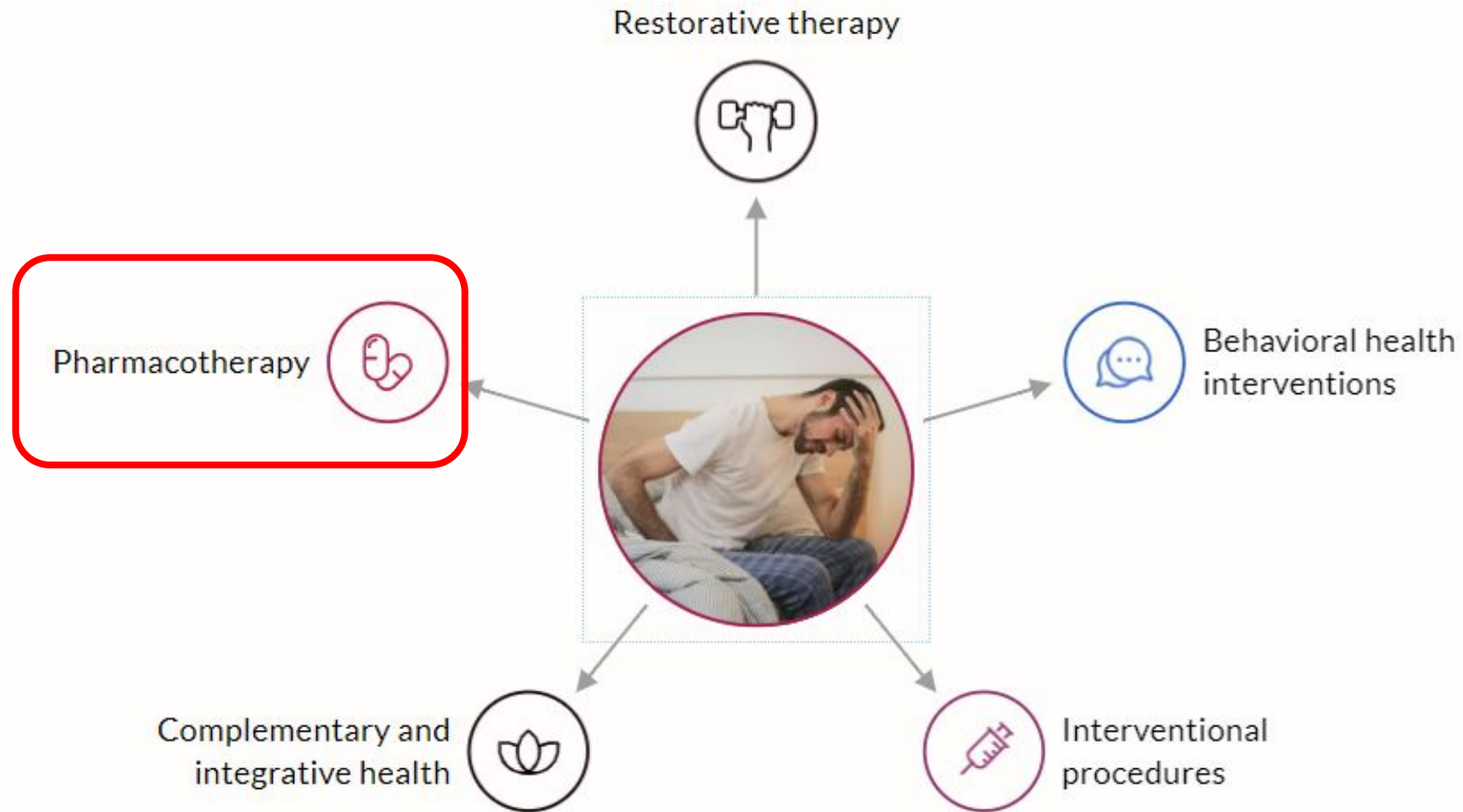
- 20+ peer-reviewed manuscripts and textbook chapters related to pain management and/or SUDs
- ~\$3 million in grant funding from agencies including NIH

## **Servant Leader**



- Founding member and past president, Society of Pain and Palliative Care Pharmacists
- Past chair of pain special interest groups within other professional pharmacy organizations

# Approach to Pain Management



# Starting Medications for Pain

- Benefit vs. risk
- Labeled indication vs. off-label/experimental
- Response may not be “one size fits all”
- Goal-directed treatment
- Part of a comprehensive treatment plan



# Talking to Providers about Medications

**Take the Initiative to Ask Questions**

**Learn How to Take Medication and What to Expect from It**

**Understand How to Follow Up and When to Call**

# Select Medications for Pain and Symptom Management

Drug or Drug Class	Indication	Works Best When Taken:
Acetaminophen	Musculoskeletal pain	On schedule or as needed
Anticonvulsants (or antiepileptics)	Fibromyalgia, nerve pain	On schedule
Antidepressants	Fibromyalgia, musculoskeletal pain, or nerve pain with or without having a history of depression	On schedule
Muscle relaxers	Muscle pain and/or spasms	As needed
Anti-inflammatory drugs (nonsteroidals like ibuprofen; steroids like prednisone)	Musculoskeletal pain, inflammation	On schedule or as needed
Topical agents (drugs applied directly to the skin like lidocaine, capsaicin, and diclofenac)	Localized pain -Lidocaine for nerve pain -Capsaicin for nerve and/or arthritis pain -Diclofenac for arthritis pain	On schedule or as needed

# Monitoring Response to Medications

Monitor for common vs. serious side effects

- Management options
- When to report/seek medical attention

Track response and impact on pain and function

Store and dispose safely

Talk with your provider about when to reconsider treatment

# Tips for Reducing Medication Costs

Streamline medication use (“deprescribing”)

Tablet splitting

Prescribing larger quantities (90-day supply)

Samples/co-pay coupons

- Upfront savings but may cost more in the long run
- Use not allowed with government-based insurance

Discount or savings cards as an alternative to insurance

Assistance programs

# Select Patient Resources

- DAILYMED - <https://dailymed.nlm.nih.gov/dailymed/index.cfm>
- US Pain Foundation Safe Dosing Guide - <https://uspainfoundation.org/resources/>
- ACPA Stanford Guide - <https://www.acpanow.com/acpa-stanford-guide.html>
- IASP Living with Pain - <https://www.iasp-pain.org/resources/living-with-pain/>

# Team MassME at a Fun 5K Run/Walk/Roll

Team MassME participated on June 8 at McCourt Foundation Boston Waterfront.



- Join Team MassME Next year!!
- *Dates for next year to be announced*





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***“Body of Water: Performance and Community Conversation  
with Sara Nesson”***

Sunday, August 18, 2024 4pm Eastern



**Sara Nesson**

Artist, writer, and performer





## How you can help...

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